



You've Survived a TBI, but Will Your Marriage?

How to keep a relationship strong after serious traumatic brain injury.

BY GINA SHAW

On a beautiful June day in 2008, Cheryl and David Hanington were riding their motorcycles with a group of friends, on their way from their Massachusetts home to a music festival in New Hampshire. When a deer ran in front of them, David braked quickly and skidded off the road, sustaining a severe traumatic brain injury (TBI). David spent a month in a coma at Maine Medical Center in Portland. When he regained consciousness, he had to relearn everything from walking to how to play his beloved guitar. David and Cheryl also had to adjust to a relationship that was very

different from the one they had had before.

“It’s like you’re back, but you’re not—especially at first,” says David, who returned to his teaching job at a regional technical high school two years after the accident. “When I came home from the hospital, I wasn’t present emotionally in terms of our relationship. All of my focus was on getting better, so Cheryl had to take a back seat to that for a while.”

“It was difficult,” Cheryl concedes. “I tend to push myself into the background and concentrate on what David needs. He gets frustrated much easier now, and he doesn’t always interpret

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— CHERYL HANINGTON



the things people say the way they're intended. I find myself on edge a lot, trying to keep him—and us—on an even keel. It's tiring, but I do it because I love him and I know he'd do it for me.”

The closeness of the Haningtons' relationship (they frequently finish each other's sentences) has helped keep their now 38-year marriage strong even in the face of David's injuries, the strain of his recovery, and the fact that in some ways, the “old David”—the man he was before the accident—will never entirely return.

But moderate or severe TBI can take a devastating toll on a marriage or partnership. (See box, “Traumatic Brain Injury: The Basics.”) Like the injury itself, the true extent of TBI's impact on a couple may not be understood for months or years.

THE SPECTER OF DIVORCE

It's long been thought that the divorce rate after TBI is dramatically high. In her popular book, *Where Is the Mango Princess? A Journey Back From Brain Injury* (Vintage, 2001), about the aftermath of her husband's speedboat accident, the late author Cathy Crimmins recalled being told that the odds were three out of four that her marriage would end in divorce.

“Research from Denmark suggested that the rate of divorce after TBI was somewhere between 50 and 75 percent,” says Jeffrey Kreutzer, Ph.D., director of neuropsychology and rehabilitation psychology at Virginia Commonwealth University and director of Virginia's Traumatic Brain Injury Model System (TBIMS), who has been studying the impact of TBI on relationships for the past 25 years. (Neuropsychology is a branch of psychology that studies how the structure and function of the brain affect psychological functions such as memory, perception, and emotions.)

But the Denmark study was based on a sample of only about 10 families. When Dr. Kreutzer and his team conducted one of the first comprehensive investigations of marriage after TBI, involving about 150 couples, they found that the divorce rate for these families was actually lower than the national average—about 18 percent in the first five or six years.

However, that statistic can be interpreted in several ways. Some couples, like the Haningtons, remain genuinely close after a TBI, but that's not always the case. “The low divorce rate may reflect the fact that people feel guilty divorcing someone who has a severe injury,” says Dr. Kreutzer. While the divorce rate may be lower after TBI, the people in the marriage often find themselves struggling. “Our ability to keep people alive after a TBI and to help them recover has improved dramatically in the last decade. Where we haven't come a long way is on emotional and psychological recovery and sustaining relationships,” he says.

The behavioral changes that often accompany severe TBI can be difficult for partners to grapple with. For example,

someone with a significant TBI might experience sudden and intense mood swings; act impulsively; behave in ways that are socially or sexually inappropriate; get angry or aggressive easily, at what may seem to be very trivial things—and later, not remember their outburst; have trouble concentrating; and appear very self-centered and lack empathy for others.

Often, people with a serious TBI don't understand just how much they have been impaired by their injury. They may not realize that they can no longer drive, for example. Sometimes, they'll take out their anger on the person closest to them, such as a spouse or partner.

AMBIGUOUS LOSS

Rosemary Rawlins, whose husband Hugh sustained a severe TBI after a bike accident 10 years ago, described the experience in a video made with Dr. Kreutzer. “People would say, ‘It's such a miracle that Hugh survived the accident,’ and I would think to myself, ‘I don't know if he did.’ He couldn't connect with me emotionally. His eyes were vacant. He didn't sound like himself. It was terrifying,” she says.

Dr. Kreutzer calls this “ambiguous loss.” Many partners of people with TBI call it “stranger syndrome.”

“The uninjured spouse may feel that their partner is physically but not emotionally present,” Dr. Kreutzer says. “They often say, ‘I'm married to a stranger.’ The personality change that follows TBI can be profound.” Many people with TBI experience at least some of the condition's symptoms, including depression, anger and irritability, insomnia, memory impairment, and inability to focus.

“About half of people with TBI are unable to drive,” says Dr. Kreutzer. “The loss of this kind of function can make patients angry. It's not unusual to see a father with severe TBI punching the walls in frustration and screaming at the kids, and the wife afraid to leave the children alone with him. The unemployment rate for people with moderate to severe TBI is about 25 to 30 percent; former breadwinners may be home all day watching TV.”

Even the little romantic gestures in a relationship can change after TBI. Cheryl Hanington was once the envy of her friends because of the thoughtful, personal gifts David would choose for her on holidays and birthdays.

“Now I find it very hard to shop,” David Hanington says. “When our anniversary or Christmas comes, I'm at a total loss. It's overwhelming. I used to plan dinners out and weekends away, but when I try to do something like that now, I get stuck.”

Sexual intimacy is often a casualty of TBI as well. “Partners become caregivers, and sometimes they're not comfortable with the sexual role and the caregiver role at the same time,” says Dr. Kreutzer. “For example, we had one patient who had a catheter

Traumatic Brain Injury: The Basics

What Is Traumatic Brain Injury?

Traumatic brain injury (TBI) happens when a sudden trauma damages the brain, such as in a car accident, an explosion, a blow to the head in sports, or a fall. TBI can be mild, moderate, or severe. The person with a mild TBI may have no loss of consciousness, while a person with a severe TBI may be unconscious for a long period of time.

How common is TBI?

Every year, at least 1.7 million people experience TBI, according to the Centers for Disease Control and Prevention. Most of these—about 75 percent—are concussions or other mild forms of TBI.

What are the symptoms of TBI?

Symptoms of a TBI vary depending on how severe it is. Acute symptoms of a mild to moderate TBI include headache, dizziness, blurred vision, nausea or vomiting, ringing in the ears, and some memory loss for the accident. As time passes after a mild TBI, symptoms may include continued headache, irritability, difficulty concentrating, lethargy, impaired memory, difficulty planning and carrying out tasks, and disrupted sleep.

The immediate symptoms of a severe TBI include loss of consciousness, seizures or convulsions, and amnesia that can vary in how long it lasts and what time period it covers. Over time, the long-term consequences of a serious TBI can include many of the same symptoms as with a milder TBI, but in a much more severe form. A severe TBI can also cause long-term mood changes, visual and hearing difficulties, and problems with balance, coordination, memory and learning.

What treatments are available for TBI?

After the initial trauma is treated and the person's condition is stabilized, most treatments for TBI involve rehabilitation that may include some or all of the following: physical therapy, occupational therapy, speech/language therapy, physiatry (physical medicine), psychology/psychiatry, neuropsychology, and social support.

What research is being done on TBI?

Because of the increasing numbers of military personnel returning from Iraq and Afghanistan with TBI, as well as attention focused on chronic traumatic encephalopathy thought to result from repeated concussions and other forms of TBI sustained by football players and other athletes, research into TBI is extremely important. You can learn more about TBI research being sponsored by the National Institute for Neurological Disorders and Stroke (NINDS) here: ninds.nih.gov/disorders/tbi/detail_tbi.htm#193713218.

and was bowel incontinent. His health insurance paid for a home health aide, but he was too embarrassed to have the aide change his diaper and catheter, so he had his wife do it. But then she said, 'How can I have a sexual relationship with you when my role is to change your diapers when you have accidents?'"

TBI RELATIONSHIP TOOLBOX

With all of these challenges, it's no wonder that TBI sometimes precipitates the end of a marriage. To help couples avoid a downward spiral, Dr. Kreutzer and a colleague at Virginia Commonwealth University, Emilie Godwin, Ph.D., created a program specifically aimed at improving relationships for couples affected by TBI. Most previous efforts along these lines have focused primarily on the uninjured partner. Funded by the National Institute on Disability and Rehabilitation Research, it's called the Therapeutic Couples Intervention and includes seven two-hour meetings with a therapist for education, psychological support, and skill building.

While the intervention is still being studied, Dr. Kreutzer says many take-home tools have been developed that couples affected by TBI can use now to work on improving their relationships.

The first key is education. "People need to learn the common effects of TBI on cognitive function and personality, as well as the common reactions of partners," says Dr. Kreutzer. "This helps to normalize what you're going through."

Over time, this education can help the person with TBI and his or her partner understand what aspects of his or her former personality and abilities will return and what changes are going to be more permanent. That can take a while, says Janet Cromer, R.N., whose husband Alan, a dynamic physics professor, sustained a TBI after being deprived of oxygen during a heart attack. The brain damage, which Janet Cromer detailed in her book, *Professor Cromer Learns to Read: A Couple's New Life After Brain Injury* (AuthorHouse, 2010) was similar to severe TBI. (However, post-anoxic injury often has a worse prognosis than TBI, partly because TBI tends to occur in younger people, whose brains recover more quickly.)

"With Alan, we knew pretty early on that he wasn't going to come back to the intelligence that he had before or be a professor again," Janet says. "It took him a long time to even learn to read at a third-grade level. So we found a new source of hope in getting him to learn to read to the point that he could take pleasure in it again, and he became a motivational speaker for other people in rehab," she says.

The Haningtons, for their part, have come to recognize and accept that David will never be the "leader" he was before the accident. "He was the stronger of our two personalities, although I have a strong personality myself," says Cheryl. "We were a good

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blend. But now he prefers to take the back seat. Sometimes I’d like to say, ‘You decide,’ but that’s so hard for him that I try not to.”

The second component is psychological counseling. People dealing with the aftermath of TBI should not have to navigate these difficult emotional waters without trained support, Dr. Kreutzer says. “A good counselor will help you express your feelings in constructive ways.”

The Therapeutic Couples Intervention uses something called the “how am I feeling” questionnaire—a checklist given to both husband and wife. “You check off feelings that you have, such as ‘I feel lonely; I feel misunderstood; I feel worried,’” Dr. Kreutzer says. “This might be the first time that people have really reflected on and talked about their reactions. These feelings might be intense and frightening, but by expressing them, the couple learns that they are experiencing many of the same feelings—fear, anxiety, discouragement—and that it’s normal.”

Seeing a neuropsychologist was enormously helpful to Lisa Thompson*, a Ph.D. mathematician from Oregon who sustained a TBI after a fall from her bicycle in 2011. She and her husband Mark*, who have a now 10-year-old son, had to adjust to an enormous personality change: Lisa went from a hard-driving, self-employed professional to someone who found it hard to focus and couldn’t finish what she started. “I could be in the middle of trying to make dinner and then I’d start rearranging the closet,” she says. “The neuropsychologist taught me that I need to be honest with myself, and with Mark, about my limits and what I can and can’t do now.”

The final building block is skills training. “We teach people how to communicate,” Dr. Kreutzer says “The uninjured spouse has to learn to get to know this ‘different’ person better—to ask them about their feelings, what their likes and dislikes are, and how they can help.” Both partners will often need to learn new and constructive ways to manage anger, frustration, stress, and other intense emotions, he adds.

“Someone with a TBI can go from zero to sixty with anger very quickly because it takes them a while to recognize the anxiety that leads to anger,” says Janet Cromer, “so I learned to watch his cues. When he started to raise his voice or tense his hands or facial muscles, I’d ask, ‘What’s going on? What are you thinking?’ Often, it was a distorted thought that someone had insulted him or done something wrong when they hadn’t.” People with severe TBI can be easily overwhelmed because their mental processing is slowed and they have a hard time multitasking.

Janet would then help Alan (who passed away in 2005), recognize what had triggered his anger. Then, he might go to a

quiet space in his office with a book to relax for a few minutes.

Lisa Thompson’s TBI often left her rambling in conversation. “I would just go on and on, not sure if I’d made my point or not,” she says. “It annoyed Mark. He would get mad, assuming I thought he was an idiot. The counselor helped me to understand that I need to rein in my rambling, and helped Mark to realize that he needs to tell me when he understands what I say.”

For Janet Cromer and her husband, Alan, the adjustment was even greater, since his injury was much more severe. They had to completely get to know one another again.

“He lost all his memories of us as a couple. He couldn’t tell you how we met or why we fell in love,” Janet says. “That bothered me very much. We had to get to know each other again in very basic ways and find things that we liked about each other. We made a game of it. I’d say, ‘I love you,’ and he’d ask me, ‘Why? Why do you love me?’ and I’d tell him specific things. I was re-attracted to him with enormous respect for his motivation and courage in learning everything all over again.”

Janet and Alan Cromer also found new forms of romance, like going on lunch dates. “He couldn’t tolerate restaurants at dinner-time because of the crowds and stimulation, but we went for lunch and always called it a date, not just going out to lunch,” Janet says.

LEARNING TO ASK FOR HELP

Couples must learn to ask for help—something that can be harder than it sounds. “The spouse of a person with TBI can be crushed by stress,” Dr. Kreutzer says. “People often feel reluctant about asking for help, but friends and family may welcome the opportunity to show how much they care.”

The Haningtons have both made sure to maintain outside relationships to take the pressure off each other. David frequently plays cards with buddies, while Cheryl goes out to the movies with her friends. But they also caution against a too-active social life. “David gets fatigued—he goes and goes and then crashes, like a kid,” she says. “There can be a tendency to overreach and be too active. Sometimes you need to just come back to each other and regroup.”

Many people find help through brain injury support groups, such as those organized by the Brain Injury Association of America (biausa.org).

Cheryl Hanington wants to reassure other couples: “A recovery that works is possible. But you have to be willing to communicate and deal with the frustration when communication is hard.”

Lisa Thompson says that her relationship with Mark has gotten stronger in some ways since her injury. “It’s devastating to realize that you’re never coming back to be the person you used to be. It’s hard not to feel that my worth has diminished,” she says. “But he says that I’m the glue that keeps us all together.” NN

*Pseudonym used at the person’s request to protect privacy.